

FEDERATION OF FAMILIES

For Children's Mental Health

Keeping the Promise for Families:

A Discussion of Strategies and Tools for
Safeguarding Statewide Family Networks

April 2006

FFCMH Office of Policy Reform



FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH

9605 MEDICAL CENTER DRIVE, SUITE 280 ♦ ROCKVILLE, MD 20850

PHONE: (240) 403-1901 ♦ WEB: WWW.FFCMH.ORG





FOREWORD

The President's New Freedom Commission on Mental Health¹ and federal officials declared that mental health care must be:

- Consumer and family driven;
- Youth directed;
- Oriented towards recovery; and
- Must promote resilience

A children's mental health system that meets those demands relies on a national network of strong family-run organizations. Meanwhile, federal budget cuts seriously threaten the underpinning for realizing these goals - the Statewide Family Network Grant Program² is in jeopardy.

The Federation of Families for Children's Mental Health is extremely concerned about the implications of these budget cuts for the lifeline of family-run organizations. Family-run organizations provide vital information, peer support, and training for families. They help families to be more effective advocates for their children³ as well as for system transformation.

As the national family voice for children's mental health, the Federation of Families represents the collective interests and experiences of over 120 family organizations. Together, these organizations compose a united vision, reflect a common philosophy, and comprise the Federation to work together to secure a better quality of life for children, youth and their families. With its hand on the pulse of family experience across the nation, FFCMH translates those experiences into broad issues requiring advocacy for national policy reform. The Federation's policy work is realized through its extensive network, linking thousands of families and their organizations across the country with policy makers, agencies, and providers in all child-serving systems. The Federation has a pivotal role in informing members of Congress and their staff, and works with coalitions of disability organizations on federal legislation, regulations, and related national policies.

Insuring a secure future for family-run organizations warrants your immediate action! This document is a guide to action that combines information exchanged during two conference calls sponsored by FFCMH on April 18, 2006 and sample tools for use by families and their organizations. Many thanks to others who have provided information for this document to help us all be better prepared to advocate for preserving the Statewide Family Network Program and expanding resources for family-run organizations.

*Pat Hunt, FFCMH
Office of Policy Reform*

¹ Goal 2 of Achieving the Promise

² See Appendix i for more information on the SFN Program.

³ This statement is supported by the findings from the Family-driven Study of Family Involvement in Systems of Care.

PROCESS AND AGENDA

FFCMH provided two opportunities for family organizations to participate in conference calls to discuss the risk to the Statewide Family Network Program and to explore their interest in developing long-range solutions for family-run organizations. Calling options included a toll free number and various times of day to accommodate personal schedules and multiple time zones. Thirty-six registrants received the agenda in advance.

FFCMH modeled how important it is for non-profit organizations to be aware of and comply with lobbying regulations when providing information to policy makers for their consideration and/or action. An invitation to participate in the calls guided family leaders with the following messages:

If you plan to join us for this activity please use time and resources that are not supported in any way with federal funds from any grant, contract, or subcontract.

These conference calls are sponsored by the Federation of Families for Children's Mental Health using unrestricted dollars. The call and the staff time involved in this activity are not supported in any way with federal funds from any grant, contract, or subcontract.



AGENDA

April 18, 2006

- Trina Osher
FFCMH
- Issues associated with advocacy
 - Status of program cuts
 - Explanation of budget process

- Paige Pierce &
Brooke Schewe
FTNYS
- Strategies effectively used in New York and their value to the future of NY family organizations

- Trina Osher
- Network Discussion
 - Sharing the tools
 - Identifying what else is needed
 - Methods for follow up

Pat Hunt, FFCMH FFCMH Commitment

ADVOCACY & LOBBYING

Trina Osher, FFCMH Coordinator of Policy and Research, highlighted how important it is for family-run organizations to protect their organizational status by attending to regulations surrounding lobbying. Participants were encouraged to visit www.clpi.org for information regarding non-profit advocacy and lobbying. The web site includes the 158 page 2nd Edition of Bob Smucker's *The Non-Profit Lobbying Guide* for download.

Some non-profits have unrestricted resources that allow them to seek to influence the action of policy makers. Even with unrestricted resources, it is important to know how much time you can allot to such activity, whether you need to be registered to do so, and if your organization has a 501 (C) 4. It is crucial to make sure that time sheets accurately document your policy related activities and identify the source of funding for that time period – both salary and benefits. It is also essential to know the rules in your state.

STATUS OF PROGRAM CUTS

APPROPRIATIONS FY 2005	APPROPRIATIONS FY 2006	ADMINISTRATION REQUEST FY 2007	FFCMH RECCOMENDATION FY 2007
\$3.3m	\$3.4m	\$1.7m	\$4.7m

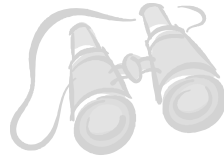
The President's proposed budget for FY 2007 cuts the Statewide Family Network (SFN) resources by 50%. Since the SFNs are supported with discretionary funds under Programs of Regional and National Significance (PRNS) in the SAMHSA/CMHS budget, the Center for Mental Health Services selects how the money designated for those programs is expended. Even though the Center could decide to fund SFNs at their current level for FY 2007, they will have fewer resources to do so if the President's proposed budget passes. Cuts would then extend beyond FY 2007. To permit a reduction in resources without strong grassroots advocacy sends the unintended message to Congress and the President that our networks do not justify preservation. Such a message undermines the value of family networks, making it is easier to eliminate them in the future. Families must be supported⁴ in their dire need for immediate action!

This is an Appropriations bill – and it starts in the House. The House and the Senate will vote on it separately. If the House and Senate do not agree, a reconciliation process will occur. The President, as with all legislation, then must sign or veto the bill. The budget process should be complete prior to September 30th.

Advocates can follow the activity of Appropriations by visiting www.house.gov , and later at www.senate.gov A full committee list follows.

⁴ See Appendix ii for tips on supporting family involvement

House Full Committee			
Majority Members		Minority Members	
▶ Jerry Lewis, CA (R - Chairman)	view site	▶ David R. Obey, WI (D - Ranking Member)	view site
▶ C. W. Bill Young, FL (R)	view site	▶ John P. Murtha, PA (D)	view site
▶ Ralph Regula, OH (R)	view site	▶ Norman D. Dicks, WA (D)	view site
▶ Harold Rogers, KY (R)	view site	▶ Martin Olav Sabo, MN (D)	view site
▶ Frank R. Wolf, VA (R)	view site	▶ Steny H. Hoyer, MD (D)	view site
▶ Tom DeLay, TX (R)	view site	▶ Alan B. Mollohan, WV (D)	view site
▶ Jim Kolbe, AZ (R)	view site	▶ Marcy Kaptur, OH (D)	view site
▶ James Walsh, NY (R)	view site	▶ Peter J. Visclosky, IN (D)	view site
▶ Charles H. Taylor, NC (R)	view site	▶ Nita M. Lowey, NY (D)	view site
▶ David L. Hobson, OH (R)	view site	▶ Jose E. Serrano, NY (D)	view site
▶ Ernest J. Istook, Jr., OK (R)	view site	▶ Rosa L. DeLauro, CT (D)	view site
▶ Henry Bonilla, TX (R)	view site	▶ James P. Moran, VA (D)	view site
▶ Joe Knollenberg, MI (R)	view site	▶ John W. Olver, MA (D)	view site
▶ Jack Kingston, GA (R)	view site	▶ Ed Pastor, AZ (D)	view site
▶ Rodney P. Frelinghuysen, NJ (R)	view site	▶ David E. Price, NC (D)	view site
▶ Roger F. Wicker, MS (R)	view site	▶ Chet Edwards, TX (D)	view site
▶ Todd Tiahrt, KS (R)	view site	▶ Robert E. "Bud" Cramer, Jr., AL (D)	view site
▶ Zach Wamp, TN (R)	view site	▶ Patrick J. Kennedy, RI (D)	view site
▶ Tom Latham, IA (R)	view site	▶ James E. Clyburn, SC (D)	view site
▶ Anne Northup, KY (R)	view site	▶ Maurice D. Hinchey, NY (D)	view site
▶ Robert Aderholt, AL (R)	view site	▶ Lucille Roybal-Allard, CA (D)	view site
▶ Jo Ann Emerson, MO (R)	view site	▶ Sam Farr, CA (D)	view site
▶ Kay Granger, TX (R)	view site	▶ Jesse L. Jackson, Jr., IL (D)	view site
▶ John E. Peterson, PA (R)	view site	▶ Carolyn C. Kilpatrick, MI (D)	view site
▶ Virgil Goode, VA (R)	view site	▶ Allen Boyd, FL (D)	view site
▶ John Doolittle, CA (R)	view site	▶ Chaka Fattah, PA (D)	view site
▶ Ray LaHood, IL (R)	view site	▶ Steven R. Rothman, NJ (D)	view site
▶ John Sweeney, NY (R)	view site	▶ Sanford D. Bishop, Jr., GA (D)	view site
▶ Don Sherwood, PA (R)	view site	▶ Marion Berry, AR (D)	view site
▶ Dave Weldon, FL (R)	view site		
▶ Michael K. Simpson, ID (R)	view site		
▶ John Abney Culberson, TX (R)	view site		
▶ Mark Steven Kirk, IL (R)	view site		
▶ Ander Crenshaw, FL (R)	view site		
▶ Dennis R. Rehberg, MT (R)	view site		
▶ John Carter, TX (R)	view site		
▶ Rodney Alexander, LA (R)	view site		

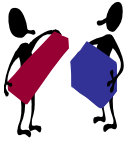


Did you find anyone from your state on the Committee on Appropriations? If so, they are essential contacts.

It is important for ALL members of Congress to have information about Statewide Family Networks (For tips & timing, see page 7)

Senate Appropriations Committee	
Majority Members (Republican)	Minority Members (Democrat)
Thad Cochran, MS – Chairman	Robert C. Byrd, WV - Ranking Member
Ted Stevens, AK	Daniel K. Inouye, HI
Arlen Specter, PA	Patrick J. Leahy, VT
Pete V. Domenici, NM	Tom Harkin, IA
Christopher S. Bond, MO	Barbara A. Mikulski, MD
Mitch McConnell, KY	Harry Reid, NV
Conrad Burns, MT	Herb Kohl, WI
Richard Shelby, AL	Patty Murray, WA
Judd Gregg, NH	Byron L. Dorgan, ND
Robert F. Bennett, UT	Dianne Feinstein, CA
Larry Craig, ID	Richard J. Durbin, IL
Kay Bailey Hutchison, TX	Tim Johnson, SD
Mark Dewine, OH	Mary L. Landrieu, LA
Sam Brownback, KS	
Wayne Allard, CO	

IMPORTANT MESSAGES



Share with your friends! Don't forget that all the folks who care about families are a great resource. "Old" friends and allies remember how important family networks are. They don't have to currently be parenting, or hold positions in agencies – they have the power of heart and the knowledge necessary for the task. "New" allies bring new resources and supports. Reach out to statewide consumer networks and support one-another's efforts. Their networks are at risk too. The foundation of this work relies on strong relationships.



Be mindful of the laws! Follow the rules regarding advocacy and lobbying! If you cannot participate in some aspects of this initiative identify others who can. Find individuals, agencies or coalitions in your community who will assist you. Find out who is likely to resist your position and move forward. (Tips for working with resistance are in the strategy section of this document)



The budget will be passed before FY 2007 (September 30, 2006)! Inform members of the House of Representatives now – and the Senate throughout the summer. Ask Representatives if they are aware of New York's "Dear Colleague" letter. If not, ask them to send one to their colleagues!



Timing is important! The budget should be passed before FY 2007. Educate members of the House now regarding the importance of family networks. Develop relationships with Senators. Pay particular attention to members of Appropriations (both House & Senate) who may represent your state. We must help them be prepared to support and defend families.



Be prepared to answer questions, provide materials, and describe the accomplishments of Statewide Family Networks or family-run organizations in your state and support these with data! Support families throughout your state to be involved in a campaign to *get the word out*. Families must be the ones who say why networks are important and ask that they be adequately funded!



Send a united message to Congress! Recommend \$4.7 Million (see page 4 for more info) Ask your member to:

- Restore the President's 2007 budget cuts to the Statewide Family Network Grant Program.
- Ask SAMHSA Administrators to make sustained funding for a comprehensive Statewide Family Network Grant Program an immediate national priority.
- Expand the Statewide Family Network Grant Program to 60 awards so that families in every state and territory and major tribe get the support they need.

NEW YORK EXAMPLE

Paige Pierce & Brooke Schewe, Families Together of New York State (FTNYS), shared recent SFN advocacy experiences that resulted in a “Dear Colleague” letter⁵ to members of Congress. It is important for your member of Congress to watch for the letter and its suggestions. The groundwork leading up to the letter is summarized in the following important tips⁶:

- **DO YOUR HOMEWORK**

FTNYS learned more about the District served by their Representative. They discovered the District is diverse in its population and geography. They questioned whether anything makes the District unusual. By finding answers to the following questions they were better prepared for a meeting: How many families does FTNYS know in the Congressman’s District? What data could FTNYS provide about this District? What impact has FTNYS made for the Congressman’s constituents? How will losing the resources for SFNs impact these constituents, the district and New York state? How will increasing those resources make a difference?

FTNYS learned about this member of Congress and their staff. In your state, you should seek answers to the following questions about your members of Congress: What is their passion? What issues have they endorsed? How can you connect supporting Statewide Family Networks to those issues?

- **ESTABLISH A RELATIONSHIP**

Getting in the door is made easy by “using who you know”. People who know your Member of Congress or someone on their staff can assist you. If that is not your case, don’t be held back from making a call to schedule an appointment. If they know you are bringing a member of their district along, you will not be refused.

- **PROVIDE “IN-SERVICE” SUPPORT**

Once inside, FTNYS was prepared to present information and data that mattered. They provided more information about the population they represent and the overall benefits of their organization. They described the implications of the program and budget cuts and illustrated them with examples of the impact on people who live in their Congressman’s district.

- **SUPPORT FAMILY PARTICIPATION**

Families need information and support to effectively advocate for their networks. Ask families in your state what they need to be good advocates for the Statewide Family Network Grant Program and help them find it.

- **FOLLOW UP & FOLLOW THROUGH**

Stay in touch with your Members of Congress and their staff. They may have new questions or information. Send them thank you notes for the time they spent with you. Acknowledge how important their support is to families who are their constituents and youth who will be voting constituents. Promptly follow up on any offer or request to provide additional information or develop solutions.

⁵ See following page

⁶ See Appendix ii for additional tips

FFCMH COMMITMENT

Realization of the recommendations of the President's New Freedom Commission on Mental Health, the ensuing Federal Action Agenda, the work of state Mental Health Planning and Advisory Councils, and the philosophies that underpin the work of System of Care communities, **ALL** weigh upon the backs of consumers and families of children and youth. The difference that exists between the weights of reliance and commitment must be balanced with resources for us to shoulder this work.

Pat Hunt, Director, Office of Policy Reform, explained the importance of a long-range strategy for achieving the level of support necessary for family networks dedicated to children's emotional and behavioral health.

The Statewide Family Network Grant Program is funded with discretionary resources. There are many programs that can be funded with the money in this line item. How much, if anything goes to each program is at SAMHSA's discretion. This leaves the statewide family organizations to rely on the goodwill of others. It also leaves them vulnerable to personal and political agendas, changing leadership, diverging interests within and among agencies and influence from shifting socioeconomic priorities.

The time is **now** for consumers, families and their organizations to work together toward lasting solutions. A strong program for our nation of grassroots networks must be developed. Such a program must also include evaluation and technical assistance adequate for their success.

The Federation is committed to working with state and national leadership to accomplish this task. Precedence for such action has been set in other arenas and will serve us well in our advocacy.

FFCMH is organizing a team dedicated to action on this issue and is exploring the interest of adult consumer organizations in joining this effort.

A companion document or series of papers is forthcoming to support you throughout both short and long-term solutions. Meanwhile, please watch for and respond to any

CALL TO ACTION - SAVING OUR NETWORKS!

S A M P L E S



SAMPLE handout for your members of Congress.

Insert your logo or use your letterhead!

Add your data and examples from family stories in your state!

STATEWIDE FAMILY NETWORKS NEED YOUR SUPPORT!

WHAT DO THE STATEWIDE FAMILY NETWORKS DO?

Name your state – describe what your network does

WHY IS OUR FAMILY NETWORK IMPORTANT?

Families raising children with emotional, behavioral, or mental disorders need emotional support, accurate information about mental health services, and help protecting the rights of their children. Family-run organizations are the best means of getting this kind of help. Research on systems of care has indicated that strengthening families enhances resilience in children.

WHAT HAS OUR FAMILY-RUN ORGANIZATION ACCOMPLISHED?

- o Make a list
- o More
- o more

Who Can You Talk To About Statewide Family Networks?

Please contact us at insert contact information

What can you do?

- Restore cuts to the Statewide Family Network Grant Program in the President's 2007 budget.
- Expand the Statewide Family Network Grant Program to 60 awards so that families in every state and territory and major tribe get the support they need.
- Establish an evaluation program to document the impact of Statewide Family Networks.
- Expand technical assistance to insure Statewide Family Networks have the best tools to be effective in meeting the needs of families and supporting transformation of the mental health system.
- Ask SAMHSA Administrators to make sustained funding for a comprehensive Statewide Family Network Grant Program a national priority.

Our chapter of the Federation of Families for Children's Mental Health serves families throughout (state). Congressional support for the SAMHSA administered Statewide Family Network Program makes a difference for # children, youth and their families in (state)!



SAMPLE TELEPHONE SCRIPT

Please read page 4 to become familiar with the facts prior to making a call to Congress.

Adapt this sample to your own specific situation.

Hello _____ {name or title of person you are calling, i.e. Congressman XYZ}

My name is _____ {full name}. I am a parent of a child who has mental health issues and our family lives in your District – We are from {City or Town}.

I am calling to let you know how concerned I am about the funding for our statewide family network. The President proposed a 50% cut in funding for this program in his 2007 budget.

(Name of the family organization) is very important to our family and other families in our community and our state. Because of (name of the family organization) I have been able to/ my child has been able to/families have been able to: {state 3 brief points why the organization is important to you}.

1)

2)

3)

Many families in your District need the support of our statewide family network. The President's proposed budget will be devastating to us. The Statewide Family Network Program is administered through the Substance Abuse Mental Health Services Administration, Center for Mental Health Services using discretionary funds designated for Programs of Regional and National Significance (PRNS). We need you to:

- Restore cuts to the Statewide Family Network Grant Program in the President's 2007 budget
- Ask SAMHSA Administrators to make sustained funding for a comprehensive Statewide Family Network Grant Program an immediate national priority.

I am asking you to support funding this program for fiscal year 2007 with 4.7 million dollars. Is that a commitment you can make to our families? {If the answer is yes – express your appreciation. If not, ask why - and what commitment they will make}. How will you keep me informed about the status of this budget item?

I appreciate your time and have enjoyed talking with you today. I would be pleased to send you more information or to talk with you further if you have questions. I can be reached at {phone number} and am available to meet with you or your staff.



The National Family Voice for Children's Mental Health

(Date)

To be addressed to all House and Senate members of the Labor-HHS-Ed Subcommittee on Appropriations (**See pages 5 & 6**)

Dear (Senator X):

The undersigned organizations urge you to restore the 50% cut in funding for Statewide Family Networks proposed in the President's 2007 budget and provide a modest increase to sustain the program. Specifically, we request you support a total of \$4.7 million for the Program. The Statewide Family Networks are a grant program administered by the Child, Adolescent and Family Branch (CAFB) of the Center for Mental Health Services (CMHS) in the Substance Abuse and Mental Health Services Administration (SAMHSA) using discretionary funds designated for Programs of Regional and National Significance (PRNS).

Families play a critical role in their children's lives. Families face extraordinary challenges when they have a child with a serious emotional, behavioral, or mental health problem. In such cases, families need emotional support, accurate information about mental health services, and help protecting the rights of their children. Growing evidence suggest that engaged, trained, and empowered family members are an essential ingredient of systems of care and are more satisfied with outcomes for children¹.

Statewide Family Networks have been a major provider of support services for families. They offer accurate and understandable information, referral, emotional support, peer-to-peer support, training, and leadership development. They have been effective in introducing a clear and strong family voice into system change and policy development. These are essential to insuring that "parents are the decision-makers in the care for their children"² as articulated in the New Freedom Commission's report and the Federal Action Agenda for Transforming Mental Health Care in America.

The Statewide Family Networks grant program is the only federal initiative that specifically is designed to enhance State capacity and infrastructure to be more oriented to the needs of children and adolescents with serious emotional, behavioral, and mental health needs and their families and to ensure that families are the catalysts for transforming the mental health and

¹ S. Hodges, T. Nesman, & M. Hernandez. *Promising practices: Building collaboration in Systems of Care. Systems of Care: Promising practices in children's mental health Series 1, Volume VI.* Center for Effective Collaboration and Practice, American Institutes for Research, Washington, DC, 1999; T. Osher & D. Osher. *Collaborating with Families* in *The Journal of Child and Family Studies* Vol. 11 No.1, 2002.

² www.samhsa.gov/Federalactionagenda/NFC

related systems in their State. The grantees accomplish this by strengthening coalitions with policymakers, program administrators, and service providers; promoting leadership and management skills development for boards and staff of the grantees; and providing technical assistance to improve the quality of life for children with mental health needs and their families. Several of the grantees in the Statewide Family Network Program specifically focus on the needs of ethnic minorities and rural families' issues.

A study of the impact of the Statewide Family Network Grants³ found that family members interviewed felt that they were better able to advocate for their children, were more in control of their lives, and were able to make lasting changes because of the help and support that they received through the statewide family networks. During 2003-2004 s the Statewide Family Network grantees provided services to 158,459 family members and youth. In the same period, 33 grantees reported that 2,905 family members and youth held seats on a mental health policy board or commission in their community or state.

Statewide Family Networks have contributed to the overall improvement of state and community children's mental health policies and services in many ways. Examples include: working cooperatively with the state mental health authority and the state legislature to develop a home- and community-based waiver (KS); facilitating a team planning process to safely and successfully maintain juvenile sex offenders in the community (GA); and making policy recommendations to eliminate the practice requiring families to relinquish custody of their child in order to get mental health services (MD).

The importance of funding from the Center for Mental Health Services to support the infrastructure of family networks needs to be underscored and cannot be understated. Most funding sources will only fund specific programs or services – not the administrative cost associated with maintaining an organization and communication network. Without continued funding at the current level, many of these modest, yet critical, family-run organizations will be forced to close their doors depriving thousands of families and youth with much needed help that they cannot get anywhere else.

All of the organizations signing on to this letter will appreciate your full support for adequate funding for this much needed program. A request for \$4.7million is a modest but sound and cost effective investment in America's families and children.

Sincerely,

Federation of Families for Children's Mental Health
Coalition ABC
Etc.

³ Mary J. Longley & Kelly Blankenship. *Benefits of Statewide Family Networks for Children's Mental Health": Voices of Family Members*. Research and Training Center on Family Support and Children's Mental Health, Portland State University, Portland, OR 1998.

STRATEGIES



CONSIDER MULTIPLE STRATEGIES

We hope the following strategies inspire you to think about ideas that will work in your state. Samples are available in the following section of this publication.



Establish relationships with policy makers! Remember those who are campaigning for office this year. Now is a great time to inform them of the importance of Statewide Family Networks (SFN). Publicly ask for their commitment to SFNs for the children, youth and families they represent. Staying in contact with local staff helps to reinforce the messages you send to members of Congress.



Letter writing campaigns can be effective! Since delivery of mail is often delayed for members of Congress, consider writing to your local office, or sending your message via fax. E-mail messages may receive immediate attention but they are limited in size.



Make telephone calls! Pre-planned calling dates can have impact. Avoid making all the calls on the same day unless it is the optimum opportunity for input. Create group lists, each with an assigned date for calling their members of Congress. Provide a script (see samples). When possible, provide toll free numbers to families.



Sponsor events that draw attention to the issue! Members of Congress may be in your state for weekends, holidays and scheduled breaks. Ask local staff to help you get them involved in your event. Though formal meetings can be important, BBQs, picnics, art shows and other festive occasions can help your member of Congress meet more constituents who can help you spread the word about the importance of family networks! More relaxed atmospheres permit them to listen and learn.



Market your successes! A media campaign can help you get the word out. Newspaper articles, flyers, community forums, and press briefings can have impact. Make sure members of Congress and their local staff are invited. Use these ideas to promote and preserve SFNs.

ESTABLISHING A RELATIONSHIP FOR POLICY WORK - getting started

GET TO KNOW YOUR ELECTED OFFICIALS

It is important to know the names of your elected officials, their background and their special interests. Visiting your state's legislature's website or going to the clerk's office will help you learn more about them. Sending newly elected officials a card of congratulations gives you a chance to let them know that you will be contacting them for an appointment soon. Before you make a visit find out about their party affiliation, committee assignments and positions, length of legislative service, and voting record. Knowing how they vote on things important to you can help you assess how much information they need. Knowing more about their family, occupation, hobbies, or community service can help you establish rapport with them when you meet. Use what you learn to help present your issues in a context that they can relate to.

Face to face meetings are a good way to get to know them and to express your views on children's mental health. It is important to make appointments in advance and be flexible with your schedule. Introduce yourself as a constituent. You may be asked to meet with their staff aides. Since key staff may be more familiar with children's or other policy issues, meeting with them is just as important as meeting with your elected officials. Aides will advise your legislator or member of Congress of your concerns at the right moment.

PROVIDE RELEVANT INFORMATION

Know what message you want to convey. Basic background on children's mental health includes how it affects you, your family, and others in the community. Be brief and to the point. Support what you say with documentation, such as fact sheets, data, articles, publications, and information from state plans. Deliver a fact sheet that documents the nature and extent of children's emotional and behavioral or mental health issues and offers solutions. Fact sheets can help you demonstrate the positive outcomes possible with effective services and supports; and show how treating such problems can prevent disruption in the lives of children or youth and their families. Fact sheets should frame the issue, background, your position and suggest action. Many children's mental health advocacy organizations have fact sheets that you could use or adapt¹. Too much information may confuse, distract or overwhelm public officials. Capture their interest by summarizing information on a cover sheet. If they don't agree with you, avoid arguments and offer to get more information. Offer solutions to the problems you mention.

FOLLOW UP & FOLLOW THROUGH

Ask for action and be prepared to be part of the solution. If you have made a commitment to provide them with additional information or could not answer their questions, connect them with other resources. You may want to invite them to speak to your family organization. FOLLOW THROUGH. If you are responsive, they will remember to contact you! When you get home, send the people you met a "thank you" note. Offer to help when legislation is drafted, bills are introduced, and hearings and workgroups are convened. Keep other families and family-run organizations informed so they can do the same. *Don't stop now - you just got started!*

STAY FOCUSED!

Use the following tool to plan an event that helps you achieve your policy objective. Keep your message brief and to the point. Leave room for questions.

[illegible]

SUPPORT FAMILIES!

SUPPORT FAMILIES TO SHARE THEIR PERSPECTIVES

1) What are the most important concerns affecting children in your community who have mental health issues?

INFANTS & TODDLERS:

SCHOOL-AGED CHILDREN:

ADOLESCENTS:

2) How is your network important to families in your state? Congress needs to hear from families!

INFANTS & TODDLERS:

SCHOOL-AGED CHILDREN:

ADOLESCENTS:

3) Are families who represent the full spectrum of issues and ages contacting policy makers?

4) Who is missing? What do they need for support in order to be included?

GUIDE FOR LETTER OF INVITATION

REMINDER

Letterhead should include the names of all sponsoring organizations.

Pay attention that titles and name spellings are correct.

Make it easy for your guest to check their calendar and reserve the date.

Emphasize the name of the statewide network and of the professional who has the most (positive) recognition in your area.

Offer something they can promote.

Recognize them as being important to children & families.

Multiple signatures can strengthen the message that the briefing is important.

BODY OF LETTER

{Date}

The Honorable {fill in name}

{Official affiliation, e.g. County Council, State Senate}

{City, State, Zip code}

Dear _____: {insert official title} _____ {Last name}

We are inviting you to a Policy Briefing {title} on **{day of week and date in bold}** from **{time in AM or PM in bold}** in {name or number} room of the {name of facility or hotel}. We will be serving {breakfast or lunch} and look forward to you joining us.

The briefing will highlight the significant role of (name of organization) and its value to our state and communities. Family members of children and youth with mental health issues and (name of professionals speaking) will describe how the statewide family network has {explain theme of this presentation – e.g. better quality of life; cost savings; strong partnerships; achieved significant policy change; other things realized by this program}

We hope that you or a staff member can attend the briefing to learn more about the mental health needs of children and their families in {name of invitee's community or state} and what you can do to improve their quality of life.

Based on successful efforts across the country, we believe you will find the strategies and solutions to be presented at the briefing will result in a more efficient use of public resources; provide more effective care; and ensure that outcomes are coupled with accountability.

Thank you for your ongoing dedication to children and families. Please RSVP to {contact name} at {phone number} of {contact organization} by {date}.

Sincerely,

{name & title}

{name of family-run organization}

{name & title}

{other significant sponsor – look for name recognition with public officials}

TIPS FOR WORKING WITH RESISTANCE

- Listen earnestly - speak honestly
- Discuss how you will work together - agree upon the rules that promote a safe environment
- Build upon your agreements
 - Explore philosophical agreements or points of unity
 - Clearly define the scope of what you agree to work together on
- Honor commitments
- Respect the views of others
- Recognize and understand "fears"
- Establish trust by building agreement one point at a time
- Promote and model accountability
 - Be prepared for and alert to *divide and conquer* strategies that impede the work
 - Follow through with promises
 - Be prepared to document the source of your information
- Stick to the goal and move forward
- Demonstrate win-win solutions

A P P E N D I X





THE STATEWIDE FAMILY NETWORK GRANT PROGRAM

The purpose of the Statewide Family Networks program is to enhance State capacity and infrastructure to be more oriented to the needs of children and adolescents with serious emotional disturbances and their families. Recognizing that family members are the best and most effective change agents, the program is designed to ensure that families are the catalysts for transforming the mental health and related systems in their State. The grantees accomplish this by strengthening coalitions with policymakers, program administrators, and service providers; promoting leadership and management skills development for boards and staff of the grantees; and providing technical assistance to improve the quality of life for children with mental health needs and their families. Several of the grantees in the Statewide Family Network Program specifically focus on the needs of ethnic minorities and rural families' issues. Statewide Family Network activities are all critical to supporting the implementation of "Transforming Mental Health Care in America: the Federal Action Agenda" developed and being promoted by the Substance Abuse and Mental Health Services Administration.¹ SFN activities include:

- Developing and conducting peer support groups helps families: address issues of bias, intolerance, shame, guilt, and blame; and offers them opportunities to learn how to constructively and successfully manage their own child's disorder; and actively participate in care planning for their child and family.
- Disseminating information and technical assistance through clearinghouses, websites, newsletters, sponsoring conferences and conducting workshops changes attitudes, reduces stigma and discrimination, transfers knowledge, and links families to resources.
- Providing outreach to families through toll-free telephone numbers and information and referral networks provides them with accurate information and prepares youth and family members to make good decisions about their care and services so they can request and obtain what they need.
- Serving as a liaison with various human service agencies and educating state and community leaders about effective ways to improve children's services. This includes highlighting gaps in services, unmet needs for care, limited access to services, and degrees of effectiveness of specific treatments.
- Training develops skills for effective and successful organizational leadership, responsible management, financial independence and sustained advocacy to improve children's mental health services.

¹ www.samhsa.gov/Federalactionagenda/NFC

WHY ARE STATEWIDE FAMILY NETWORK GRANTS IMPORTANT?

Families raising children with emotional, behavioral, or mental disorders need emotional support, accurate information about mental health services, and help protecting the rights of their children. Research on systems of care has indicated that strengthening families enhances resilience in children².

The Surgeon General³ recognized that families have become essential partners in the delivery of mental health services to children and adolescents. Family-run organizations linked to a national network are the means by which families can fulfill this important role. The Goal 2 of the final report of the President's New Freedom Commission on Mental Health envisions a transformed mental health system that is "consumer and family driven"⁴ and states that, "Local, State, and Federal authorities must encourage consumers and families to participate in planning and evaluating treatment and support services."⁵ The Federal Action Agenda, developed by the substance Abuse and Mental Health Services Administration to implement the Commission's recommendations, states very clearly that, "A keystone of the transformation process will be the protection and respect of the rights of adults with mental illnesses, children with serious emotional disturbances, and their parents."

Growing evidence suggest that engagement of trained and empowered family members is an essential ingredient of systems of care and can result in increased family satisfaction and better outcomes for children⁶. Statewide Family Networks are critical to achieving full participation of families in planning, designing, implementing and evaluating services for children with emotional, behavioral, or mental disorders.

Statewide Family Networks have been a major provider of support services for families in the form of information, referral, emotional support, peer-to-peer support, training, and leadership development. They have also been effective in introducing family voice into system change and policy development. These outcomes are essential to insuring that "parents are the decision makers in the care for their children"⁷ as articulated in the New Freedom Commission's report and the Federal Action Agenda for Transforming Mental Health Care in America.

² Phyllis Gyamfi, Bhuvana Sukumar, & Ann Webb Price. *What factors contribute to resilient adaptation in children with serious emotional disturbance?* Paper presented at the 15th Annual Research Conference sponsored by the University of South Florida, Tampa, Florida in March, 2002.

³ *Report of the Surgeon General's Conference on Children's Mental Health: A National Agenda*. Department of Health and Human Services, 2001.

⁴ President's New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America*. U. S. Department of Health and Human Services, July 2003, page 35.

⁵ Ibid. page 45.

⁶ S. Hodges, T. Nesman, & M. Hernandez. *Promising practices: Building collaboration in Systems of Care. Systems of Care: Promising practices in children's mental health Series 1, Volume VI*. Center for Effective Collaboration and Practice, American Institutes for Research, Washington, DC, 1999; T. Osher & D. Osher. *Collaborating with Families in The Journal of Child and Family Studies* Vol. 11 No.1, 2002.

⁷ www.samhsa.gov/Federalactionagenda/NFC

EVIDENCE OF EFFECTIVENESS

A study of the impact of the Statewide Family Network Grants⁸ groups the benefits received into three categories:

1. Information on legal rights, specific disorders, and resources;
2. Emotional support consisting of parent-to-parent sharing, understanding and friendship, staff as advocates to support families, and training for advocacy at a higher policy level; and
3. Practical services including workshops, financial support and respite care.

Family members interviewed for the study felt that they were better able to advocate for their children, were more in control of their lives, and were able to make lasting changes because of the help and support that they received through the statewide family networks.

The importance of funding from the Center for Mental Health Services to support the infrastructure of family networks needs to be underscored. Most funding sources will only fund specific programs or services – not the administrative cost associated with maintaining an organization and communication network. The 1998 report evaluating this program found that the organizations receiving repeated years of funding were more viable entities, able to raise funds from other sources and able to conduct more extensive and vigorous support and advocacy.⁹

The Statewide Family Networks Government and Performance and Results Act Report (GPRA) for 2003-2004 states the Statewide Family Network grantees reported providing at least one services to 158,459 family members and youth. In the same period, 33 grantees reported that 2,905 family members and youth held seats on a mental health policy board or commission in their community or state.

ACCOMPLISHMENTS OF STATEWIDE FAMILY NETWORK GRANTS

Statewide Family Networks have contributed to the overall improvement of state and community children's mental health policies and services in many ways. Some examples are:

- Keys for Networking in Kansas worked cooperatively with the state mental health authority and the state legislature to develop a home- and community-based waiver that allows families to be authorized service providers in Kansas.
- The Georgia Parent Support Network contracts with the state to operate a network of specialized foster homes. They also facilitate a team planning process to safely and successfully maintain juvenile sex offenders in the community.
- A study by the Maryland Coalition of Families for Children's Mental Health stimulated the Governor to appoint a commission which made policy recommendations to eliminate the practice requiring families to relinquish custody of their child in order to get mental health services.
- United Advocates for Children of California was a critical partner ensuring that family members participated in the stakeholder group drafting the Mental Health Services Act (Proposition 63) and making sure services consistent with system of care values and principles would be provided to children and youth.
- Mississippi Families As Allies, in collaboration with the business community and state legislators, developed policy support for community based services delivery for children and adolescents with serious emotional disturbance.
- The Florida Institute for Family Involvement developed a nationally recognized, comprehensive family-to-family response to hurricanes and other disasters including an extensive website and tip sheets in several languages to help families of children with mental health needs be better prepared to respond to and recovery from the trauma caused by natural disasters.

⁸ Mary J. Longley & Kelly Blankenship. *Benefits of Statewide Family Networks for Children's Mental Health*: *Voices of Family Members*. Research and Training Center on Family Support and Children's Mental Health, Portland State University, Portland, OR 1998.

⁹ Longley & Blankenship



Supporting Youth & Family Voice

Answering these questions with youth and families will help you know how to support their involvement in saving the Statewide Family Network program!

Assist youth and families in effectively sharing their experiences by:

- **Getting Youth & families involved**

- How can you reach young adults and families who have had benefit of the network? How can you include them?
- How can you include families who have experienced various aspects of the service system?
- What are the risks for them? How can you help assume those risks? (Particularly if custody or other issues jeopardize their safety)

- **Keeping youth & families involved**

- How will you ensure their voices are constant and resounding?
- What tangible, practical and flexible resources do they need in order to fully participate? (telephone scripts; pizza party for letter writing or story telling; etc.)
- What information do they need and how will it be communicated to them?
- How will they know they have been heard? Appreciated? (Provide updates as change happens; track their involvement – set a goal and use a scale or other visual aid to encourage participation; send thank you notes or calls)
- Do they have peers involved in all of the work?

- **Helping youth & families be effective**

- Do they need assistance in being able to effectively relate the relevant details of their stories?
- Are you seizing opportunities for them to share their information? Creating new opportunities? (examples may include hosting an educational event for child serving state and local agencies; public forums; round table discussions, letter writing campaign, etc.)

- **Using what youth & families offer**

- How will they see their collective efforts?
- What are their strengths?
- How will they drive the change?



A Checklist for Policy Action

- ☐ ✓ **Prioritize** the policy issue you identify based on:
 - Experiences of youth & their families
 - Realities of political, social & economic environment
 - Internal & external factors
 - Source, nature & extent of allies & opposition
- ☐ ✓ **Shape** the message – it should transcend all economic, geographic, social, political and cultural arenas.
- ☐ ✓ **Create** common language and clear definitions so everyone understands the message.
- ☐ ✓ **Support** the position with data, reports, state plans, etc.
- ☐ ✓ **Provide** tangible & logistical support for family involvement.
- ☐ ✓ **Identify** natural allies.
- ☐ ✓ **Promote** joint ownership.
- ☐ ✓ **Explore** unintended consequences (keep what works!).
- ☐ ✓ **Develop** a P R campaign – use the best merchants - present information that relates to the frame of reference & experiences of others.
- ☐ ✓ **Frame** the issue within the context of reports, tools, data, current circumstances, etc.
- ☐ ✓ **Identify** existing system foundations that can support, implement & sustain the change you are seeking
- ☐ ✓ **Work with resistance**
- ☐ ✓ **Keep** the high road
- ☐ ✓ **Demonstrate** win-win solutions
- ☐ ✓ **Understand & utilize** protocols & processes
- ☐ ✓ **Meet** your legislators & get to know them
- ☐ ✓ **Create** opportunities & **seize** unexpected moments
- ☐ ✓ **Discover** & become familiar with buildings & hearing rooms
- ☐ ✓ **Prepare, practice & provide** testimony that is relevant to the policy issue
- ☐ ✓ **Ask for a commitment** to action
- ☐ ✓ **Monitor** how commitments are honored
- ☐ ✓ **Celebrate** successes!

Pat Hunt



Shaping the Message

The message you create determines how your initiative is viewed by “the world”.

Creating a message that everyone can own is important – that means having a message that speaks to all economic, geographic, social, political and cultural arenas. The message garners its strength & vitality from the fact that it IS “boundless” – drawing new support as it gains its own identity. An inclusive message offers fewer opportunities for resistance to mount.

Branding the message with a logo or phrase provides instant recognition. Think about how readily you recognize the “Just Do IT!” of Nike, the “golden arches” of McDonald’s or “flying windows” of Microsoft programs.

Use a logo and tag line to convey your message. Develop a plan with strategies for effectively marketing the message. Employ various tools and tactics specifically for getting the attention of each audience with whom you communicate.



WHAT IS THE MESSAGE?

HOW WILL IT BE RECOGNIZED?

DOES IT BLAME, OMIT OR OFFEND OTHERS?

CAN PEOPLE WHO ARE INVESTED IN THE CURRENT STATUS ENDORSE IT?

HOW WILL YOU ENSURE THAT IT IS CONVEYED IN THE SPIRIT INTENDED?

WHO ARE YOUR BEST MERCHANTS? WHAT IS YOUR PUBLIC RELATIONS PLAN?





Some Tips for Shaping Your Message

- ***Be concrete, not abstract.*** Use real stories to show how the lives of children, youth, and families will change. “Before” and “after” scenarios can be very effective especially when supported with data.
- ***Keep the message simple.*** Use ordinary language as much as possible. Explain special terms like “wraparound” or “systems of care” in words that everyone will understand.
- ***Give the broad picture- avoid too many details.*** Policy makers hear about many different issues every single day. You want them to remember yours. Present the “big picture” and do not distract their attention with too many specific details.
- ***Use a message that compels the audience to act.*** Convey the urgency of your policy objective. Make the issue relevant to everyone in the audience, regardless of whether they know a young person who has a serious mental health problem. Clearly state what you want your primary audience to do that will achieve your policy objective.
- ***Use data wisely.*** Policy makers want to hear evidence of the benefits to the community such as what the initiative will cost and how it will save funds elsewhere.
- ***Give families an opportunity to emphasize the positive.*** Families can best explain how the policy you are promoting will help their children and improve the quality of their lives and the community. Have a diverse and wide range of families share brief vignettes to illustrate how universal the solution will be.

Select the best merchants to carry the message you have defined.

Best merchants have:

- A solid *understanding* of the issue
- The *skill* to communicate it well
- The *respect & trust* of others



Using Data

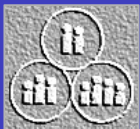
DATA has powerful messages! Though they can be questioned, they are not emotional, irrational, angry or having unrealistic goals. If not enough data exists, work together to define HOW to get the information you need. Show how existing data relates to your position.

Being able to use systems information to support your position is crucial to making policy changes. Information about waiting lists for services, unmet needs and existing litigation are powerful tools for supporting your work. Past reports, studies, and formal recommendations of previous groups, administrations and legislatures strengthen your position. Make sure that your position builds on current state & local plans, since they are also tools for change.

TIPS FOR USING DATA TO SUPPORT YOUR POLICY OBJECTIVE

- Keep it simple.
- Use data that shows significant changes over time.
- Use the most recent available data.
- Use data that shows why your policy objective will help the community and families.
- Present real life stories to illustrate the story behind what the numbers really mean for children, families, and the community.

- Do you have data that support sustained funding for Statewide Family Networks?
- What information do you still need? How will you get it?
- Do family stories illustrate the implications of the data?
- Where is your data published or available so others can look at it?
- How can others use the data to support sustaining these family networks?
- Where and how do you strategically disseminate information?



FEDERATION OF FAMILIES

For Children's Mental Health

Please direct questions about this document to:
Pat Hunt
Office of Policy Reform
(207) 225-2435